

## The NCER-PD brain donation programme

### Information for medical doctors

#### 1/ What is the brain donation programme?

*Some people, with or without brain disease, choose to make their brain available for research after their death. Brain donation is an important part of research into neurological diseases: donating one's brain can provide tissue for numerous studies.*

*In Luxembourg, the National Centre of Excellence in Research on Parkinson's disease (NCER-PD) is in charge of the first brain donation programme, launched in 2019 and approved by the Comité National d'Éthique dans la Recherche (CNER). NCER-PD collects post-mortem human brains from participants of the Luxembourg Parkinson's Study, who have additionally decided to contribute with their brains to research on Parkinson's disease once they pass away.*

*By creating a repository of brain tissue, which accepts donations from people with or without brain diseases, this initiative will contribute to the Luxembourg Parkinson's Study but might also become useful for other ongoing research programmes. In the long run, it will contribute to prevent, diagnose, treat and cure disorders of the human brain.*

#### 2/ How does it work?

*When a person decides to donate their brain for biomedical research, the Laboratoire National de Santé (LNS) and the Luxembourg biobank (IBBL) collect the tissue post-mortem, prepare it for future use in research, and stores it according to the highest standards. The tissue is then made available to qualified researchers working on scientific projects after an evaluation by an experienced sample access committee. The brain bank ensures compliance with ethical and scientific standards as well as donors' privacy protection.*

#### 3/ Good to know if your patient is a registered donor

- *Your patient (or a legal representative) signed a consent form allowing NCER-PD to collect the brain tissue of the donor after death. The form was signed in the presence of a medical doctor who clarified any questions of the donor.*
- *The NCER-PD team recommends registered brain donors to inform their family doctor of their choice. It can be helpful when a donor passes away, to ensure that procedures are quickly carried out. However, this is not mandatory.*
- *In case of death outside the hospital, the NCER-PD team will ask the family of the donor to contact you and to inform you of his decision to donate his brain. The death certificate that you will deliver is necessary to carry out the donation.*
- *Once the certificate has been delivered, the brain tissues will be removed during a clinical autopsy. The post-mortem examination will be carried out by a neuropathologist at the LNS, ideally within 24, but up to 96 hours after death.*
- *For patients, the brain tissue will allow a definitive diagnosis of the underlying cause of parkinsonism.*

#### **4/ For more information**

*Detailed information and an extensive FAQ are available on the website:*

[www.parkinson.lu/brain-donation](http://www.parkinson.lu/brain-donation)

*You can also contact the NCER-PD team to know more about brain donation:*

*Parkinson Research Clinic - 00352 4411 4848 - [parkinson@chl.lu](mailto:parkinson@chl.lu)*

*A NCER-PD team member is on call between 8:00 and 17:00 from Monday to Friday.*

*Outside these time slots, you can leave a message and the team will contact you back as soon as possible.*